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Social development challenges faced by persons with albinism

Report of the Secretary-General

Summary

The present report contains a discussion of the main social development challenges faced by persons with albinism, taking into consideration the specific challenges faced by women and children and primarily focusing on the barriers in access to health, education, employment and participation in political, social, civic and cultural life. Drawing upon the collective promise of the 2030 Agenda for Sustainable Development to "leave no one behind", the present report provides a framework for conceptualizing and removing those barriers to social inclusion and a description of existing policy responses. Recommendations are made to Member States, the international community, civil society organizations and the private sector.

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I. Introduction

1. In its resolution 70/229, the General Assembly expressed concern that persons with albinism[1] were disproportionately affected by poverty, owing to the discrimination and marginalization that they faced, and recognized the need for resources to develop and implement programmes to prevent and combat prejudice and to create an environment conducive to respecting their rights and dignity. The Assembly requested the Secretary-General to present a comprehensive report on the social development challenges faced by persons with albinism at its seventy-second session.

2. The present report provides an overview of those issues, taking into consideration the specific challenges faced by women and children and primarily focusing on the barriers in access to health, education, employment and participation in political, social, civic and cultural life.

3. In December 2016, a questionnaire was sent to Member States, non-governmental organizations and United Nations entities. Responses were received from 13 States,[2] 15 non-governmental organizations,[3] and the United Nations Children's Fund (UNICEF). All examples of the social challenges faced by people with albinism included herein refer to examples provided in the responses, unless otherwise specified. The present report also includes the input of the Independent Expert on the enjoyment of human rights by persons with albinism and the Department of Economic and Social Affairs, as well as a review of the literature relevant to the topic.

4. Owing to the absence of disaggregated national statistics, information on the social situation of persons with albinism is generally deficient. There is relatively more information on the human rights situation of this population in sub-Saharan Africa, given that the issue was brought to the fore in response to reports of horrendous physical attacks against persons with albinism in some countries. Despite this information gap, testimony gathered by the Independent Expert, academic publications and news pieces, suggest that persons with albinism face similar patterns of social exclusion and discrimination worldwide.

5. In response to the reported attacks against persons with albinism, the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Independent Expert have addressed human rights violations affecting persons with albinism, including attacks, killings, desecration of graves, trafficking in body parts, displacement, discrimination based on disability and colour, and challenges concerning the rights to the highest attainable standard of health and to education.[4]

6. The present report is focused on the social development challenges affecting persons with albinism. Social development is concerned with processes of change

[1] Albinism is a rare, non-contagious, genetically inherited condition that affects people worldwide regardless of ethnicity or gender. It is characterized by a significant deficit in the production of melanin which results in the partial or complete absence of pigment in the skin, hair and eyes (see A/HRC/24/57).

[2] Azerbaijan, Brunei Darussalam, Cameroon, Djibouti, Egypt, Guatemala, Ireland, Kenya, Malawi, Niger, Tunisia, United Republic of Tanzania and Zambia.

[3] Valeurs albinos, Albinos sans frontières, Organisation des personnes albinos du Burundi, Association pour la promotion des albinos au Cameroun, Bibliothèque le Pavillon Blanc, Association nationale des albinos de Côte d'Ivoire, Association Ivoirienne pour la promotion des femmes albinos, United Albinos Association of Liberia, Association of Persons with Albinism in Malawi, Albino Foundation, Nigeria Yerni Dada, Standing Voice, Association nationale des albinos du Togo, Community Services Program in Uganda and Zimbabwe Albino Association.

[4] For further information on the work of OHCHR and the Independent Expert, see www.ohchr.org/EN/Issues/Albinism/Pages/IEAlbinism.aspx.

that lead to improvements in human well-being, social relations and social institutions. The aim of social development is to enable all people to reach their full potential.

7. Social development is closely related to social inclusion, which is the ability of all individuals to participate fully in economic, social, political and cultural life. Discrimination and the lack of access to services and material resources are the main barriers to social inclusion. Promoting social inclusion requires both removing barriers to participation and taking active steps to improve the terms of participation in society for people who are excluded. The latter entails enhancing access to opportunities (education, health and other services), access to resources (employment and income opportunities) and participation in social, political, civic and cultural life.[5]

8. Inclusiveness and shared prosperity are the core aspirations of the 2030 Agenda for Sustainable Development. The 2030 Agenda is underscored by a collective promise to "leave no one behind", with an endeavour to start with "the furthest behind first". This promise and endeavour also apply to persons with albinism.[6]

9. Furthermore, the general principle of equality and non-discrimination is a fundamental element of the human rights framework. The latter guarantees the full enjoyment of all human rights for persons with albinism on an equal basis with others. It supports the full and effective participation of persons with albinism in society, notably by prohibiting all forms of discrimination, including on the basis of colour and disability.[7]

10. While the present report provides an overview of the barriers that persons with albinism may face and identifies solutions hereto, it does not systematically assess the magnitude of the social exclusion that effectively results from the barriers. Additional reliable information will be necessary in order to have a better understanding of the extent and depth of the social development challenges faced by this population.

II. Overview of the social development situation of persons with albinism

11. The proportion of persons with albinism varies by region. Although no recent thorough and incontestable numbers exist, estimates indicate that 1 in 17,000 to 20,000 people are affected by oculocutaneous albinism in North America and Europe,[8] while in sub-Saharan Africa the occurrence varies from 1 in 5,000 to 1 in

[5] *Leaving no one behind: the imperative of inclusive development, 2016 Report on the World Social Situation* (United Nations publication, Sales No. E.16.IV.1). Available from www.un.org/development/desa/dspd/report-on-the-world-social-situation-rwss-social-policy-and-development-division/rwss2016.html.

[6] Ibid.

[7] For a general overview of the work of OHCHR in the area of equality and non-discrimination, see www.ohchr.org/EN/AboutUs/Pages/Enhancingequalityandcounteringdiscrimination.aspx.

[8] The National Institutes of Health in the United States of America estimates the frequency of oculocutaneous albinism worldwide to be 1 in 20,000 (see http://ghr.nlm.nih.gov/condition/oculocutaneous-albinism). The National Organization for Albinism and Hypopigmentation, a national group serving persons with albinism in the United States, reports the frequency of albinism to be 1 in 18,000 to 1 in 20,000 in the United States (see www.albinism.org/site/c.flKYIdOUIhJ4H/b.9253761/k.24EE/Information_Bulletin__What_is_Albinism.htm).

15,000, depending on the country.[9] The frequency is much higher in certain geographically isolated communities and in specific groups where marriage between cousins is common, with reported rates higher than 1 in 1,000.[10]

12. Persons with albinism face discrimination and barriers that restrict their participation in society on an equal basis with others. As a result, they are more likely to experience social exclusion and poverty. Discrimination through mockery, bullying and name calling, normalized isolation and segregation, restricted access to health services and the denial of reasonable accommodation are some of the challenges faced by persons with albinism worldwide. The stigma of albinism also affects family members, notably mothers, who may experience events that have a strong and negative impact on their psychological and social well-being.[11]

13. The lack of opportunities that results from the inadequate provision and uneven geographical distribution of public services (education, health, transport, water and sanitation, among others) is another important driver of social exclusion. The insufficient provision of public services affects persons with albinism disproportionately and hence increases their risk of social exclusion. In general, persons with albinism living in remote areas risk greater social exclusion that those living in urban areas. Similarly, those living in lower-income countries have fewer opportunities to develop their capabilities.[12]

A. Intersecting forms of discrimination faced by persons with albinism

14. Discrimination is a major driver of social exclusion that continues to underpin group-based socioeconomic differences worldwide.[13] Article 2 of the Convention on the Rights of Persons with Disabilities defines discrimination as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field".[14]

15. Persons with albinism experience discrimination based on multiple and intersecting grounds, notably colour, disability, gender, race and age. Hypervisibility is one of the root causes of the lack of acceptance and stigmatization of persons

[9] In 2005, the World Health Organization carried out a pilot survey on albinism in Nigeria, South Africa, the United Republic of Tanzania and Zimbabwe,. For the results, published in 2006, see Esther S. Hong, Hajo Zeeb and Michael H. Repacholi, "Albinism in Africa as a public health issue", *BMC Public Health*, vol. 6 (2006) and A/HRC/24/57, para. 14.

[10] The frequency of 1 in 1,000 was reported among the Tonga in Zimbabwe (Patricia M. Lund and others, "Oculocutaneous albinism in an isolated Tonga community in Zimbabwe", *Journal of Medical Genetics*, vol. 34, No. 9 (1997)), 1 in 832 among the Vhatavhatsindi in South Africa (Patricia M. Lund and others, "Oculocutaneous albinism in a rural community of South Africa: a population genetic study", *Annals of Human Biology*, vol. 34, No. 4 (2007)) and 1 in 200 to 300 among the Cuna in Panama (Östen Björnberg, "Total albinos among the Cuna Indians", *Journal of the History of Medicine and Allied Sciences*, vol. XV, No. 3 (1960)).

[11] This amounts to "discrimination by association" which is "discrimination against persons on the basis of their association with a person with a disability" (Committee on the Rights of Persons with Disabilities, general comment No. 3 (2016), para. 17 (c)).

[12] "On average, urban residents have better access to education, health care and other basic services than rural residents." For further information on social exclusion, see *Leaving no one behind: the imperative of inclusive development*.

[13] Ibid.

[14] The right to freedom from discrimination is recognized in the Universal Declaration of Human Rights and enshrined in international human rights law through its inclusion in the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.

with albinism. This is especially true in societies where the majority of the population has dark skin; but discrimination based on colour has also been reported in predominantly white communities, where persons with albinism are discriminated against for being "too white". Persons with albinism also experience discrimination on the basis of disability, including denial of reasonable accommodation.[15]

16. Persons with albinism may also experience further discrimination based on gender, age, race and other grounds. For example, in countries where there continues to be a de facto division of society along racial lines and skin colour is relevant to social integration, persons with albinism in dark-skinned communities are likely to experience double marginalization: for belonging to that community and for being different from members of their community.[16]

B. Disparities across regions

17. With the exception of the attacks and ritual killings, which have been reported only in some countries, the issues faced by persons with albinism are global in nature.[17] The degree to which these problems occur, however, and the impact on the lives of individuals vary by country, depending on, among other things, the general level of socioeconomic development, the availability of resources, social norms and climate.

18. While discrimination against persons with albinism is a worldwide phenomenon, patterns of discrimination are context-specific and vary in intensity depending on the social norms of the country, including the degree to which the human rights-based approach to disability has been embedded into national norms and practices, the perception of colour differences, historical experiences of racial discrimination, the level of public awareness and accurate information about the condition. For example, the stigma experienced by persons with albinism in the West, where the medical explanation for albinism is dominant, is completely different from the experience of persons with albinism living in regions where mythical and supernatural explanations prevail.[18]

19. In lower-income countries, the overlapping processes of exclusion put persons with albinism at risk. In these countries, public services and basic infrastructure are insufficiently developed. Health-care systems are underresourced. According to the Human Development Index, there are, on average, less than 2 physicians per 10,000 people in countries characterized by low human development, compared with more than 40 physicians per 10,000 people in countries characterized by very high human development. The relatively small share of the population with at least some secondary education (between 5 and 57 per cent) illustrates the fact that education standards are generally low in countries characterized by low human development. Public services are unevenly distributed, with marked inequalities between rural and urban areas. Even though basic services are relatively more accessible to the urban population, basic infrastructure remains insufficient in most cities. This makes

[15] On the multiple forms of discrimination that people with albinism face, see http://albinism.ohchr.org/human-rights-dimension-of-albinism.html or Michael Hosea, "Perspective: living with albinism, discrimination and superstition" available from www.unicef.org/sowc2013/perspective_hosea.html.

[16] Ibid.

[17] See A/HRC/31/63.

[18] For an example of a person with albinism living in a region where supernatural explanations prevail, see Michael Hosea, "Living with albinism": "practitioners of witchcraft hunt and kill us to use our hair, body parts and organs in charms and potions".

access to health care, education and other public services disproportionately difficult for persons with albinism, especially for those living in remote areas.[19]

20. Reports by the Independent Expert and other available information show that a combination of factors makes the situation of persons with albinism in of sub-Saharan Africa particularly worrying. In this region, the overall low socioeconomic development situation has a disproportionate impact on persons with albinism. In 2016, 33 of 46 countries of sub-Saharan Africa, were characterized by low human development and 11 by medium human development, according to the Human Development Index. The gross domestic product per capita in sub-Saharan Africa ranges between $562 and $28,272, with a regional average of around $4,900 (8.5 times less than in countries characterized by very high human development).[20] In these countries, between 24 and 60 per cent of the national population lives below the poverty line. One third of the population lives in urban areas, with an annual urbanization rate of 3.5 per cent.[21] Rural-urban migrants are largely employed in the informal sector, which represents 61 per cent of urban employment.[22]

21. The hypervisibility of persons with albinism in predominantly dark-skinned populations makes them particularly vulnerable to stigmatization. The proximity of countries in sub-Saharan Africa to the equator exposes persons with albinism to extreme ultraviolet radiation and exacerbates their risk of developing skin cancer. This risk is particularly acute for persons with albinism who live in rural areas and are likely to be outdoors during daylight hours. The combination of poor living conditions, discrimination and witchcraft beliefs and practices tend to exacerbate the occurrence of attacks in the region. As discussed by the Independent Expert, discrimination in the region takes extreme forms, including infanticide, physical threats, attacks and ritual killings linked to myths and witchcraft.[23] Physical attacks against persons with albinism have been reported in 26 countries. Rapid policy responses are all the more needed given that the proportion of persons with albinism in sub-Saharan Africa is comparatively high.[24]

C. Legal and policy frameworks for addressing social development challenges faced by persons with albinism

22. The international human rights framework protects the rights of all persons, including persons with albinism. The general principle of equality and non-discrimination that applies to all persons is contained in the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.

23. Given the intersecting nature of discrimination that they face, it has been debated whether persons with albinism are subject to further protection under the

[19] For further information on inequality and human development, see *Human Development Report 2016: Human Development for Everyone* (United Nations publication, Sales No.: E.16.III.B.1). Available from http://hdr.undp.org/en/2016-report.

[20] See A/HRC/31/63.

[21] Urbanization in Africa, available from www.afdb.org/en/blogs/afdb-championing-inclusive-growth-across-africa/post/urbanization-in-africa-10143/.

[22] African Development Bank and others, *African Economic Outlook 2012: Promoting Youth Employment* (Paris and Tunis: 2012). Available from www.africaneconomicoutlook.org/sites/default/files/content-pdf/AEO2012_EN.pdf.

[23] See A/71/255 and A/HRC/34/59 and Add. 1-2.

[24] See A/HRC/34/59 and A/71/255.

Convention on the Rights of Persons with Disabilities[25] and the International Convention on the Elimination of Racial Discrimination. Both the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Racial Discrimination[26] have addressed the situation of persons with albinism in their concluding observations and recommendations. By doing so, they have recognized that persons with albinism fall under the protection of the respective conventions. Further protection can also be found in the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women.

24. The intersecting approach is particularly well suited to understand discrimination faced by persons with albinism because it takes into account historical, social and political contexts and thus recognizes the unique experiences of persons who have been the targets of discrimination on more than one ground.

25. Regarding discrimination on the basis of disability, the human rights-based approach is particularly well suited to promoting the social inclusion of persons with albinism. In the preamble to the Convention on the Rights of Persons with Disabilities, disability is conceptualized as the result of "the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". This approach supersedes previous understandings of disability, including the medical and charitable approaches, that focused more on the individual's impairment and less on the disabling effects of society.

26. The 2030 Agenda for Sustainable Development provides an important policy framework for promoting the social inclusion of persons with albinism. Inclusiveness and shared prosperity are the core aspirations of the 2030 Agenda; these mean that every person should benefit from prosperity and enjoy minimum standards of well-being. Target 10.2 of the Sustainable Development Goals recognizes that certain people are at higher risk of exclusion than others and thus emphasizes that everyone should be included, "irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status". Accordingly, the 2030 Agenda is underscored by a collective promise to "leave no one behind", with an endeavour to start with "the furthest behind first". This promise and endeavour apply to persons with albinism.

27. Furthermore, the 2030 Agenda sets forth Sustainable Development Goals and targets that are highly relevant to the situation of persons with albinism, notably the targets focusing on persons with disabilities, for example, equal access to education (targets 4.5 and 4.A); to full and productive employment and decent work (target 8.5); to transport systems (target 11.2 and public spaces (target 11.7); empowerment and promotion of social, economic and political inclusion (target 10.2); and increased availability of high-quality, timely and reliable data disaggregated by disability

[25] The Committee on the Rights of Persons with Disabilities has addressed the situation of persons with albinism and formulated recommendations, notably under the provisions of article 5 on equality and non-discrimination (CRPD/C/UGA/CO/1, para. 8), article 8 on awareness-raising (CRPD/C/ETH/CO/1, paras. 17-18 and CRPD/C/UGA/CO/1, paras. 14 and 15 (c)), article 10 on the right to life (CRPD/C/ETH/CO/1, paras. 21-22 and CRPD/C/KEN/CO/1, paras. 19 and 20 (a)-(c)), article 19 on living independently and being included in the community (CRPD/C/UGA/CO/1, para. 39 (c)), and article 25 on health (CRPD/C/UGA/CO/1, paras. 50 and 51 (c)). The Committee's thematic considerations on the situation of persons with albinism do not preclude the implementation of the treaty in its totality to persons with albinism.

[26] In its concluding observations on a periodic report of South Africa, the Committee on the Elimination of Racial Discrimination addressed the situation of persons with albinism, expressing concern at the discrimination and stigmatization faced by persons with albinism on the basis of "colour" (CERD/C/ZAF/CO/4-8, paras. 20-21).

(target 17.18). Other relevant targets include the call for appropriate social protection systems (target 1.3); access to economic resources (target 1.4); reduced vulnerability and impact building resilience to economic, social and environmental shocks and disasters (targets 1.5 and 11.5); ending hunger (target 2.1); access to adequate and equitable sanitation and hygiene (target 6.2); and eliminating discrimination (targets 10.3 and 16.B).

III. Specific barriers to social development faced by persons with albinism

A. Barriers to access to health services

Vision services

28. The accommodation of the needs of persons with albinism concerning their particular vision impairment is an essential prerequisite for them to fully develop their potential and participate in social life.[27] Albinism includes vision impairment in nearly all cases, resulting from refractive (myopia, hyperopia and astigmatism) and non-refractive (notably nystagmus, photophobia and strabismus) impairments. In most cases, these impairments can be improved with the use of optical devices. Refractive errors can be corrected with glasses, contact lenses and low vision aids, including magnifiers, handheld telescopes and screen magnifiers. Wearing tinted lenses or lenses with special filters while outdoors protects the eyes from bright light and ultraviolet rays.[28]

29. Several studies indicate the low use of vision care devices by persons with albinism, especially in low-income countries.[29] A lack of awareness among care providers and by persons with albinism about their visual impairment partly explain this situation, as does the difficult access to ophthalmological services owing to transportation and affordability issues. In low-income countries, optical services are often concentrated in urban areas and thus are not easily accessible to people living in remote areas. Additional barriers include lack of supply, absence of accessible support, lack of repair shops for optical devices and poor social acceptance of the devices.

Preventive and curative measures relating to skin cancer

30. Persons with albinism have high skin sensitivity to ultraviolet radiation that makes them highly vulnerable to skin cancer, sunburn, rashes and premature skin ageing. The risk of developing skin cancer is about 60 times less for persons with dark skin than for persons with fair skin.[30] The head and neck are more likely to be

[27] The Convention on the Rights of Persons with Disabilities establishes the right to reasonable accommodation.

[28] See, for example, Mrinali Patel Gupta "Albinism and low vision" available from www.visionaware.org/info/your-eye-condition/guide-to-eye-conditions/albinism-6165/125.

[29] N. N. Udeh and others, "Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population", *Journal of Community Health*, vol. 39, No. 3 (2014); Patricia M. Lund, "Health and education of children with albinism in Zimbabwe", *Health Education Research*, vol. 16, No. 1 (2001); Patricia Lund and Retha Gaigher, "A health intervention programme for children with albinism at a special school in South Africa", *Health Educational Research*, vol. 17, No. 3 (2002); and Paul Lynch, Patricia Lund and Bonface Massah, "Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi", *International Journal of Educational Development*, vol. 39 (2014).

[30] O. N. Agbai and others, "Skin cancer and photoprotection in people of colour: a review and recommendations for physicians and the public", *Journal of the American Academy of Dermatology*, vol. 70 (2014).

affected than other body parts. Without adequate protection, persons with albinism are likely to develop premalignant and malignant lesions at an early age and suffer from advanced skin cancers in their third or fourth decade of life.[31] Skin cancer is a major cause of morbidity and mortality of persons with albinism, resulting in shorter life expectancy for this population.[32]

31. Personal sun protection and effective public health policies can significantly reduce the harmful effects associated with sun exposure. Protective practices consist of sun avoidance, wearing protective clothing and wide-brimmed hats and applying high-protection sunscreen. Early health advice by nurses and midwives, awareness-raising on the harmful effects of ultraviolet radiation and on sun protection options and regular preventive dermatological consultations all play an important role in preventing skin cancer. Persons with albinism would benefit from public health policies that provide systematic detection, treatment and follow-up schemes for skin cancer.[33] The most common treatment consists of surgery combined with adjuvant or palliative radiotherapy.

32. Persons with albinism do not always use sun protection and dermatological services owing to their limited access to these services and/or to a lack of awareness. For example, some medical practitioners have advised mothers of children with albinism to expose their child to the sun in order to tan their light skin. The information available on the practices of persons with albinism with regard to sun protection focused largely on the situation in sub-Saharan Africa. It shows that sunscreen is not widely available there, is often unaffordable and it is often not on the national list of essential medicines. When affordable sunscreen is available at local hospitals, the cost and time involved in travelling to collect it deter many families. As with ophthalmological services, dermatological services are scarce and concentrated in urban areas.[34] This is one of the main reasons, in addition to financial constraints and popular recourse to traditional healers, why persons with albinism with skin cancer tend to present themselves late at dermatological hospitals. Moreover, the scarcity of clinical resources and the lack of funding often lead to premature termination of treatment.

Other barriers

33. Persons with albinism face other barriers to achieving the highest attainable standard of health,[35] including the unaffordable cost of health-care services, coupled with the lack of health insurance schemes and generally low socioeconomic condition. The absence of health-care services in remote and rural areas, marginalization and lack of community support are other significant barriers.

34. Stigma and discrimination are sources of depression and anxiety among persons with albinism and may also deter them from seeking medical help. For example, a study conducted in Nigeria showed that persons with albinism with

[31] Samson Kimayo Kiprono, Baraka Michael Chaula and Helmut Beltraminelli "Histological review of skin cancers in African albinos: a 10-year retrospective review", *BMC Cancer*, vol. 14 (2014).

[32] In 2002, the Zimbabwe Albino Association revealed that the life expectancy of person with albinism was 43 years, compared with 57 years for the total population of Zimbabwe.

[33] The Committee on the Rights of Persons with Disabilities has recommended that persons with albinism be included in cancer policies, paying specific attention to people living in rural areas. It has also recommended providing grants for affordable skin-care protection for persons with albinism in order to realize the right to live independently and to be included in the community (CRPD/C/UGA/CO/1, para. 39 (c)).

[34] For example, there is only one public hospital providing dermatological services in the United Republic of Tanzania.

[35] The right to the achievement of the highest attainable standard of health is inscribed in article 12 of the International Covenant on Economic, Social and Cultural Rights.

HIV/AIDS were reluctant to make use of free and available antiretroviral therapy services because of the fear of being further stigmatized.[36] Persons with albinism may also be denied access to adequate healthcare because of the ignorance of medical practitioners. For example, a woman with albinism from Malawi reported that doctors refuse to prescribe contraceptive pills to her because of the colour of her skin.[37]

B. Barriers to access to education

35. The right to inclusive education means that all persons should have access to education without discrimination and on an equal basis with others, and to be valued and accommodated according to their capabilities and value, as established in article 24 of the Convention on the Rights of Persons with Disabilities. Goal 4 of the Sustainable Development Goals affirms that inclusive and equitable education is essential for the social development of all. This would include persons with albinism. When needed, reasonable accommodation should be provided to support pupils with albinism, including shutters on windows, mobile blackboards, allowing them to sit at the front of the classroom and walk up to the board, provision of devices to help those with visual impairment, large-print materials, a copy of the teacher's notes and extra time to complete reading tasks. To reduce direct sun exposure, they should be offered the opportunity to sit away from direct sunlight and to stay in the shade in the school playground. The school uniform should also be flexible in its design to ensure that pupils with albinism can wear trousers, long-sleeved shirts and hats throughout the year.

36. In practice, however, pupils with albinism often have limited access to education. All State respondents reported high dropout rates and low educational attainment among persons with albinism.

37. Multiple barriers prevent persons with albinism from attaining higher education levels. Some parents keep their child with albinism away from school or discourage them from pursuing higher education. When they do have access to education, children with albinism are often educated in segregated educational environments (for example, special schools for blind persons), which are not conducive to social inclusion. Furthermore, misconceptions and misbeliefs, in conjunction with prejudices against persons with albinism, may result in the exclusion of children with albinism from schools. Reported cases from the Asia-Pacific region illustrate the reluctance of some school authorities to accept children with albinism owing to the fear of contagion or as a result of pressure from the parents of other children.

38. Under article 24 of the Convention on the Rights of Persons with Disabilities, pupils with albinism have the right to attend mainstream educational institutions. However, such inclusion can be challenging when institutions are not prepared to receive them. The appearance of children with albinism and the misbeliefs that surround their condition may lead to a lack of acceptance. Discriminatory comments from peers and teachers have been reported in several countries. Moreover, teachers in mainstream educational institutions are often misinformed and seldom trained in

[36] Bayo Aluko-Olokun and Adeola Abayomi Olaitan, "Skin cancer risk factor reduction in Africa: assessment of use of antiretroviral therapy services by human immunodeficiency virus positive albinos", *HIV & AIDS Review*, vol. 14, No. 1 (2015).

[37] Amaury Hauchard, "Femia, albinos au Malawi: 'le médecin refuse de me donner la pilule à cause de ma peau'", *Le Monde*, 2 March 2017. Available from www.lemonde.fr/afrique/article/2017/03/02/femia-albinos-au-malawi-le-medecin-refuse-de-me-donner-la-pilule-a-cause-de-ma-peau_5088026_3212.html.

ways to support pupils with albinism. Inclusion is especially challenging in countries where the education system is understaffed and crowded and has poor infrastructure.

C. Barriers to access to employment and income opportunities

39. Access to employment and other income opportunities, such as land ownership and loans, is an essential aspect of participation in social life. Beyond being a source of material wealth, income-generating activities also confer social identity and acceptance. Article 27 of the Convention on the Rights of Persons with Disabilities guarantees the right to "the opportunity to gain a living by work freely chosen or accepted in the labour market and a work environment that is open, inclusive and accessible", which includes of persons with albinism.

40. All State respondents reported that persons with albinism were more likely to be unemployed and to experience material deprivation. A survey conducted among persons with albinism in the United Republic of Tanzania showed that 53 per cent of the active population surveyed was unemployed, 40 per cent self-employed and 7 per cent formally employed.[38] When persons with albinism have access to employment, they are more likely to be in low-paying jobs, at lower occupational levels and with poor prospects for promotion and poor working conditions. That they are often engaged in the informal sector without social protection and struggle to make a living makes access to health-care services even more difficult, if not impossible.[39]

41. Persons with albinism face multiple barriers to access to income-generating activities. Misconceptions about persons with albinism, notably that they are less productive or have intellectual disabilities, may deter employers from hiring them. Some employers do not hire them simply because they refuse to adapt the workplace to accommodate their needs. Others are reluctant to hire persons with albinism for reasons related to their different appearance, especially in posts where the employee is in contact with the public. It is even more difficult for persons with albinism to find a decent job when they have not been given the chance to complete higher education.[40]

42. Other barriers include difficulties in securing loans to start businesses as these may be avoided by potential customers owing to myths and misbeliefs about albinism. The Association of Persons with Albinism in Malawi reported that that population was labelled as a risk group by loan institutions and small village loan savings groups.

D. Other barriers to full participation in society

43. Persons with albinism face discrimination in accessing to social protection programmes. Consultations held in 2016 in the United Republic of Tanzania by a non-governmental organization, Standing Voice, and the World Bank revealed that persons with albinism were refused State support for low-income families on the

[38] L. N. Kiprono and others, "Quality of life and people with Albinism in Tanzania: more than only a loss of pigment" *Open Access Scientific Reports* (2012). Available from www.omicsonline.org/scientific-reports/srep283.php.

[39] See, for example, Standing Voice on the situation in the United Republic of Tanzania: "Those who graduate, often leave school ostracised and unskilled, with only 7 per cent finding formal employment", at www.standingvoice.org/albinism.

[40] See A/71/255.

incorrect grounds that they were thought to be supported by external donors.[41] The Convention on the Rights of Persons with Disabilities, in article 28 (2) (b), requires States to ensure the right of all persons, including those with albinism, to enjoy social protection programmes without discrimination.

44. Stigma and discrimination also have an impact on the access of persons with albinism to adequate housing. Cases of landlords refusing to rent accommodation to persons with albinism because of fear that they would run away overnight to escape attack have been reported in Malawi and Zambia.[42]

45. Persons with albinism also experience exclusion from marital and family life. Testimony from several countries bears witness to the difficulty in finding a husband or wife and being accepted by in-laws.[43] The difficulty of having a marital life is particularly devastating in societies where marital status is a key determinant of social status, social inclusion and access to various rights.

46. In some countries, the inadequate capacity of the judicial system to address cases of discrimination, the absence of legal aid and adequate legal representation deter victims from seeking help. This perpetuates a vicious cycle of exclusion for persons with albinism who are victims of discrimination and attacks.[44]

47. In regions where albinism and prejudice regarding the condition are prevalent, persons with albinism seldom participate actively in politics, as they face and fear discrimination. However, in Kenya, there are two persons with albinism represented in the political system: a Minister of Parliament and a Judge of the High Court.

48. Persons with albinism also face barriers in access to some public services owing to discrimination and lack of accommodation. Respondent States reported difficulties for persons with albinism in reading prints on public transportation signage, and the absence of shade at bus stops.

49. Misconceptions about albinism translate into the isolation of persons with albinism being perceived as acceptable. Exclusion from social interaction, for example, on the grounds that albinism is contagious has been reported worldwide.[45] Negative attitudes, rejection and ostracism, especially from close relatives, have a strong and negative impact on the psychological and social well-being of persons with albinism and hinder their ability to fully participate in economic, social, political and cultural life.[46]

50. The media and the arts tend to support stigma and discrimination with regard to persons with albinism by reproducing belittling, negative and caricaturized

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[41] For further information on the consultations, see: http://news.standingvoice.org/tag/world-bank/.

[42] A/HRC/34/58/Add.2, para. 28. See also The Maravi Post, "Albino woman denied access to rent house in Mzuzu; landlords fear being suspected of albino abducting and killing", 1 May 2017, available from www.maravipost.com/albino-woman-denied-access-rent-house-mzuzu-landlords-fear-suspected-albino-abducting-killing/.

[43] A survey conducted among persons with albinism in the United Republic of Tanzania indicated that 56 per cent of the respondents of marrying age were single, 30 per cent married and 14 per cent divorced or separated. Among the married respondents, 51 per cent reported problems with their partners (Kiprono and others, "Quality of life and people with albinism in Tanzania" (2012)).

[44] Article 13 of the Convention on the Rights of Persons with Disabilities provides for ensuring access to justice for persons with disabilities, including persons with albinism.

[45] The campaign by OHCHR, entitled "People with albinism: not ghosts but human beings" specifically addresses the occurrence of social exclusion, See http://albinism.ohchr.org/human-rights-dimension-of-albinism.html.

[46] See, for example, June Waugh "Social aspects of albinism" available from www.albinism.org/site/c.flKYIdOUIhJ4H/b.9260359/k.EB45/Information_Bulletin__Social_Aspects_of_Albinism.htm.

depictions of albinism.[47] Irresponsible reporting by the mass media on the attacks that occurred in sub-Saharan countries has been blamed for fuelling the attacks.[48]

E. Specific barriers faced by women and girls with albinism

51. Women and girls with albinism are exposed to multiple and intersecting forms of discrimination. They face a higher risk of sexual abuse, especially in communities where they are believed to have the power to cure HIV/AIDS or to bring good luck to the person who has sex with them.[49] They are also highly vulnerable to exploitation and abuse in the workplace.

52. Mothers of children with albinism may face rejection, ostracism and discrimination. This is common in communities where the birth of a child with albinism is considered a sign that the mother has been unfaithful.[50] This makes them, and their child, particularly vulnerable to isolation, poverty and attacks.

F. Specific barriers faced by children with albinism

53. Children with albinism are exposed to multiple and intersecting forms of discrimination. As noted by the Special Representative of the Secretary-General on Violence against Children, children with albinism are at higher risk of abandonment, stigmatization and marginalization as a result of their appearance and of their visual impairment.[51]

54. In sub-Saharan Africa, children with albinism are particular targets of witchcraft-related attacks owing to the belief that the innocence of the victim increases the potency of the witchcraft.[52] Infanticides of children with albinism have also been reported in some African countries.[53]

55. Children with albinism, and especially in marginalized groups, are exposed to a high risk of discrimination from an early age. When discrimination comes from parents and caregivers, a child is likely to develop low self-esteem,[54] which hinders his/her development of social skills and peer relationships. As mentioned above, children with albinism also experience discrimination with regard to access to education.

IV. Policies and measures addressing social development challenges faced by persons with albinism

A. International level

56. Following the report of attacks against, and killings of, persons with albinism, the situation of persons with albinism has garnered increased attention in the

[47] Charlotte Baker, "Writing over the illness: the symbolic representation of albinism", in *Social Studies of Health, Illness and Disease: Perspectives from the Social Sciences and Humanities*, Peter Twohig and Vera Kalitzkus, eds. (Amsterdam, Rodopi, 2008).
[48] A/71/255, para. 76.
[49] See A/HRC/24/57.
[50] A/71/255, para. 8.
[51] A/69/264, para. 34.
[52] See A/HRC/31/63.
[53] A/HRC/24/57, p. 9.
[54] R. J. Gaigher, P. M. Lund and E. Makuya, "A sociological study of children with albinism at a special school in the Limpopo province", *Curationis*, vol. 4, No. 25 (2002).

international community.[55] Among recent international and regional initiatives addressing the situation of persons with albinism is the creation of the United Nations International Albinism Awareness Day,[56] the appointment of the Independent Expert,[57] targeted programmes by United Nations agencies and international organizations[58] and the recent endorsement by the African Commission on Human and People's Rights of a regional action plan to end attacks on persons with albinism in Africa.[59]

B. National level

57. Although a few countries have reported specific policies for persons with albinism,[60] respondent States do not generally have such policies or legal frameworks. National laws usually include a general prohibition of discrimination and a prohibition on specific grounds. In principle, these provisions protect persons with albinism from discrimination, yet, in practice, their enforcement has many loopholes.

58. Most respondent States recognize persons with albinism as persons with impairments on the grounds of their visual impairment and, sometimes, of their skin sensitivity.[61] None of these countries recognize albinism in itself as an impairment, meaning that the impairments of persons with albinism have to be recognized under other common disabilities for them to be protected under disability policies and laws.

59. When States recognize persons with albinism as persons with impairments, those persons enjoy the specific benefits and rights granted to that population, notably in the fields of education, employment, health and participation in political life.[62]

60. With respect to education, States continue to provide special schools for pupils with visual impairment, including persons with albinism, even though there is a move towards more inclusive education.[63] Other measures commonly provided by ministries of education include the provision of large-print material for national exams, visits of specially trained teachers and, less often, the provision of free low vision optical devices in educational institutions. In Malawi, the Montfort Special Needs Education College trains teachers on the specific requirements of persons with albinism.

61. Concerning access to employment, respondent States reported several positive measures for promoting access to employment and other income-generating

[55] A/71/255.

[56] See resolution 69/170.

[57] See Human Rights Council resolution 28/6.

[58] Among ongoing projects, it is worth mentioning UNICEF programmes in the Democratic Republic of the Congo, Mozambique and the United Republic of Tanzania; the World Bank support for a research project on albinism in the United Republic of Tanzania; and the community awareness-raising pilot project by the United Nations Educational, Scientific and Cultural Organization (UNESCO) in the United Republic of Tanzania.

[59] See: www.achpr.org/sessions/60th/resolutions/373/.

[60] In Kenya, the Government has, for example, adopted a national persons with albinism sunscreen support programme.

[61] In Brunei Darussalam, albinism is considered a medical condition. In Zimbabwe, a legal framework for persons with disabilities exists, but it does not include persons with albinism. In Benin, the legal framework for persons with disabilities is deficient.

[62] Some countries, including Kenya, also help persons with albinism to prevent premature death from diseases related to sun exposure by raising awareness and providing sunscreen lotion.

[63] Three of the respondent States stressed the recent adoption of inclusive education policies.

activities for persons with disabilities, including employer quotas, tax breaks, subsidies, preference in public procurement and the creation of accessible Internet job portals.

62. Only a few States reported specific measures facilitating access to health services for persons with albinism. In the United Republic of Tanzania, the Government has recently introduced a cost-sharing policy according to which under resourced persons share the treatment cost with public referral hospitals. This policy is expected to benefit impoverished persons with albinism.

63. Although several States reported having parliamentary quotas for persons with disabilities, this does not ensure that persons with albinism would be present in a parliament, as they would compete with persons with other disabilities.

64. Other initiatives include public awareness campaigns on albinism in the mass media, the distribution of informative leaflets and the celebration of Albinism Awareness Day.

65. States do not usually produce nationwide statistics about persons with albinism. Among the respondent States, Cameroon and the United Republic of Tanzania produce disaggregated data from the national population census on persons with albinism. This idea is under discussion in other States.

C. Responses by civil society organizations

66. Civil society organizations representing persons with albinism are present in most countries. The type and range of activities undertaken by them depend largely on the situation of persons with albinism in their respective countries and the capacity of the State to provide the required accommodations. Civil society organizations are especially important in sub-Saharan Africa. In this region, their main activities include awareness-raising campaigns,[64] service provision[65] and State lobbying.[66]

V. Conclusions and recommendations

67. **Persons with albinism continue to face discrimination and barriers that prevent them from participating fully in economic, social, political and cultural life. The promise of the 2030 Agenda to "leave no one behind" creates new urgency to improve the terms of participation of persons with albinism in society and ensure that they benefit from prosperity and enjoy minimum standards of well-being. To translate this promise into genuine changes for persons with albinism, five pillars of action are critical:**

[64] The Association nationale des albinos de Côte d'Ivoire, the Zimbabwe Albino Association and the Site for Community Services Program in Uganda reported general awareness-raising activities on albinism. Valeur Albino from Benin and the Association nationale des albinos du Togo reported targeted awareness-raising activities on the risks of skin cancer.

[65] In the United Republic of Tanzania, Standing Voice provides skin cancer prevention services and optometry services through its skin cancer prevention programme and vision programme. The Regional Dermatology Training Centre of the Kilimanjaro Christian Medical College operates a comprehensive care programme for persons with albinism since 1993 and has recently entered into a partnership with UNICEF to expand its activities. The Albino Association of Malawi also has a good record of registering individuals with albinism, providing them with counselling on skin protection, fighting for their rights and raising community awareness.

[66] The Association of People with Albinism in Malawi reported that it advocated the integration of persons with albinism into the national population census.

(a) **Recognizing the multiple and intersecting forms of discrimination faced by persons with albinism, notably on the grounds of disability, colour, gender, race and age, and taking steps to combat them;**

(b) **Disseminating information and raising awareness about the situation of persons with albinism;**

(c) **Taking specific inclusionary measures to enhance access to services (education and health, among other services) and access to material resources (employment and income opportunities) for persons with albinism;**

(d) **Ensuring the participation of persons with albinism in social, political, civic and cultural life;**

(e) **Collecting, compiling and disseminating data on persons with albinism in order to identify patterns of discrimination and assess progress toward the attainment of the Sustainable Development Goals.**

A. Member States

68. **It is recommended that Member States:**

(a) **Invest in the social development of their people, in particular persons with albinism. States that have been experiencing significant economic growth should target inequality with a view to guaranteeing social development for persons with albinism and the larger public;**

(b) **Address the root causes of discrimination against persons with albinism, notably through awareness-raising campaigns that disseminate accurate information on albinism, the integration of albinism into education curricula, the promotion of persons with albinism as role models and the support to civil society organizations involved in awareness-raising activities. Awareness-raising campaigns should engage with people at the community level and be adapted to local sociocultural contexts. Persons with albinism should be involved in the design of these campaigns;**

(c) **Adopt national action plans and legislation on the rights of persons with albinism, in consultation with civil society organizations representing persons with albinism and in conformity with international human rights standards, notably the Convention on the Rights of Persons with Disabilities and the International Convention on the Elimination of All Forms of Racial Discrimination;**

(d) **Adopt measures to ensure the systematic dissemination of information on albinism to parents, educators and support-givers of children with albinism;**

(e) **Collect, compile and disseminate data on persons with albinism to identify patterns of discrimination and assess progress towards the attainment of the Sustainable Development Goals, in particular by including the variable of persons with albinism in the national population censuses and by ensuring mandatory registration of birth and deaths of persons with albinism. The collected data should be disaggregated, at least by age and sex;**

(f) **Adopt measures to ensure the accessibility, availability, affordability and quality of dermatological and visual goods and services, notably by including sunscreen and skin cancer treatment products in national lists of essential medicines;**

(g) **Include persons with albinism in public health policies for skin cancer;**

(h) **For countries where dermatological and ophthalmological services are scarce: develop and/or support outreach programmes among persons with albinism, including mobile units for skin health and ophthalmological services; adopt measures to make first-necessity items (sunscreen, sun protective clothing, sunglasses and low vision devices) accessible and affordable, especially by distributing them through existing networks of health services and educational institutions; and increase the share of public health expenditure in total government expenditure to improve the availability of dermatological and ophthalmological services;**

(i) **Promote the inclusion of pupils with albinism in mainstream education by providing educational institutions with the adequate means to equip classrooms, provide supportive devices to pupils with albinism and train teachers on albinism and supportive measures that they can take to accommodate the needs of pupils with albinism;**

(j) **Adopt and ensure the effective implementation of positive measures to promote employment and access to income-generating activities for persons with albinism;**

(k) **Ensure accessibility to social protection and poverty reduction programmes for persons with albinism;**

(l) **Support organizations representing persons with albinism and ensure their participation in all decisions and measures taken for the full implementation and enjoyment of the rights of persons with albinism;**

(m) **Adopt and ensure the implementation of so that persons with albinism enjoy access to justice, including by having appropriate remedies and redress;**

(n) **Enforce criminal laws that allow prosecution and punishment of attacks, mutilations, killings and other severe human rights violations, by establishing more severe criminal punishment when these acts are committed on the basis of discrimination, in particular when targeting persons with albinism;**

(o) **Combat stereotypical, belittling and negative characterizations of persons with albinism in the mass media and the arts, with due regard to the right to freedom of expression.**

B. International community

69. **It is recommended that the international community:**

(a) **Provide financial and technical cooperation assistance to States in support of measures that seek to prevent and combat discrimination against persons with albinism, strengthen the capacity of the health-care system in providing affordable dermatological and ophthalmological services, and strengthen the capacity of the educational system to include pupils with albinism;**

(b) **Provide financial and capacity-building assistance to civil society organizations working for the promotion and protection of the rights of persons with albinism and for the general improvement of their life conditions;**

(c) Support research projects on human rights abuses and social development challenges faced by persons with albinism;

(d) Ensure that the high-level political forum on Sustainable Development and Member States give due consideration to the social development challenges of persons with albinism in the implementation of and follow-up to the Sustainable Development Goals.

C. Civil society organizations

70. **It is recommended that civil society organizations:**

(a) Address the root causes of discrimination of persons with albinism, notably through awareness-raising campaigns;

(b) Develop programmes to provide services and information to persons with albinism, especially in places where these services are lacking;

(c) Lobby States on issues related to the human rights situation of persons with albinism and the barriers that they face in terms of social development.

D. The private sector

71. **It is recommended that the private sector:**

(a) Adopt good practices and policies against discrimination in order to ensure that persons with albinism are treated on an equal basis as other persons, especially in terms of recruitment, work conditions and opportunities and access to loans;

(b) Provide reasonable accommodation for the needs of persons with albinism in the workplace;

(c) Avoid putting persons with albinism in situations that may be harmful to them in the course of their business activities.

E. The media and arts

72. **It is recommended that media companies adopt a responsible, educational and do-no-harm editorial policy with regard to persons with albinism and promote tolerance and understanding of albinism.**